



Eczema Outreach Support

Growing our Model
What we did: 2023/24
Final Report



Overview of 2023/24

Across 2023/24, EOS's services and awareness raising work have never been more needed. The unrelenting pressures on an already overwhelmed NHS, continued underestimation of the impact of eczema and a lack of mental wellbeing support mean that children and their families have been struggling more than ever.

EOS has provided a safe, professional and supportive place for families to access the tailored support that they need, when they need it. Families know that they can trust our team to share their voices and experiences authentically to raise awareness about the realities of eczema and campaign for better support and treatment for them.

This year we have made significant developments in our service offer and communications, which we will share more on below. But significantly, we have been focused on building for the future ensuring that we have the foundations in place to meet the growing need for our work in sustainable & impactful ways. Notably this year, we have progressed with our new strategy development, which will be launched early Summer 2024, and have accelerated the delivery of our Fundraising Strategy to address the complex and challenging funding environment we are operating in.

The support from the UK Portfolio over the past four years has been life changing for EOS as an organisation and for the families we support. Without your generous funding we would not be able to say that we are truly a UK-Wide organisation operating everywhere from Penzance to the Outer Hebrides. So much has been learnt and shared by our team especially around how to engage with healthcare and education professionals. We are now fully embedded within the UK Dermatology space and can make sure that the voices of our members are heard by decision makers across parliament, the NHS and education departments.

The next year will undoubtedly bring challenges as we continue to increase our sustainability and tackle the volatile economic environment, however this should not distract from the fact that we are delivering more services and communications than ever before and our profile and position in the UK dermatology sector is growing in strength every day. By working together, we will overcome the challenges we face and ensure that EOS can do even more for families with eczema.



Suzi Holland
Chief Executive Officer

Project Activity April 2023 – March 2024

Services Report

Throughout 2023/24, the needs of families living with eczema has continued to evolve and intensify. In response, our service delivery has built on the successes of previous years and our continued commitment to work in collaboration with families with eczema.

"It has been such a relief to find support from EOS, I feel a bit more confident and knowledgeable about managing my child's eczema, although I know there is still a lot to learn and explore."

Parent, Annual Survey

Our goals	What we did to meet them in 2023/24
<p>Confidence: Families are more confident in their self-management, communication and coping skills</p>	<ul style="list-style-type: none"> • Support provided by our Youth Panel (online) to parents/carers of teens to answer questions they wouldn't ask their children • One-to-one support calls for parents/carers & 16/17 year olds • Development & launch of our High 5 Club peer support sessions to build community and grow confidence: 7 delivered • Provision of educational and fun resources for children, young people and their parents/carers on managing the condition in our Welcome Packs & at key stages in children's lives: 700 packs delivered
<p>Support: Families are more supported to deal with the condition and its impact on life, including at school and with their healthcare providers</p>	<ul style="list-style-type: none"> • Resources to improve children & young people's experiences at school & to support parents to advocate for their children's needs • 32 primary school workshops were delivered to schools across the UK • Launch of new online, health and well-being resources for families to download focused on helping children & young people manage the wellbeing impacts of eczema. • Peer support sessions for parents/carers to create a sense of community, build skills and reduce isolation: 4 sessions • A webinar giving families access to psychology professionals with specific expertise in eczema
<p>Connection: Families feel less alone and more connected with others by having access to a</p>	<ul style="list-style-type: none"> • Access to peer support in our closed Facebook Group and online sessions for carers and children • Online webinars for parents/carers to connect with others and find solutions

<p>community of peers and by being part of a supportive community.</p>	<ul style="list-style-type: none"> • Face-to-face family event Dundee to bring families together to learn, share experiences and build connections • Face-to-face events in Edinburgh & Dundee to bring families together & for children with eczema to spend time with others • Development of our TikTok channel to better engage with teenagers when and in a way they want to get support • Specialist health psychology sessions to equip children and carers with the tools and skills to manage the impact of eczema on day to day life, including on relationships.
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"It [the school workshop] really helped my teacher and classmates understand what I'm going through. People have stopped teasing me now. Everyone said how good it was. Thanks for doing a great job."

Child with eczema via handwritten card

Other Developments in 2023/24

- We developed a **resource for schools** with support from a Health Psychologist to increase awareness of the impact of eczema on school life and provide practical tools for staff to use to better support children with the condition under their care. Professionals can also sign up to access a CPD resource to further enhance their skills. We kickstarted a pilot with 400 schools across Edinburgh and the Lothians in March to understand the impact of this intervention and assess potential engagement with the CPD resource.
- Our **Eczema Care Plan** was rolled-out across the UK by our Project Lead, Sandra Lawton. Sandra networked across the UK with professionals in primary and secondary care and a range of professional organisations to raise the profile of the plan and offer support to embed it within teams. Organisations engaged included:
 - Queen's Nursing Institute (QNI)
 - Institute of Health Visiting (iHV)
 - General Practice Nurses Group (GPNG)
 - School & Public Health Nurses Association (SAPHNA)
 - Centre for Pharmacy Postgraduate Education (CPPE)
 - Health Education England
 - General Pharmaceutical Council (GPhC)
 - Royal Pharmaceutical Society

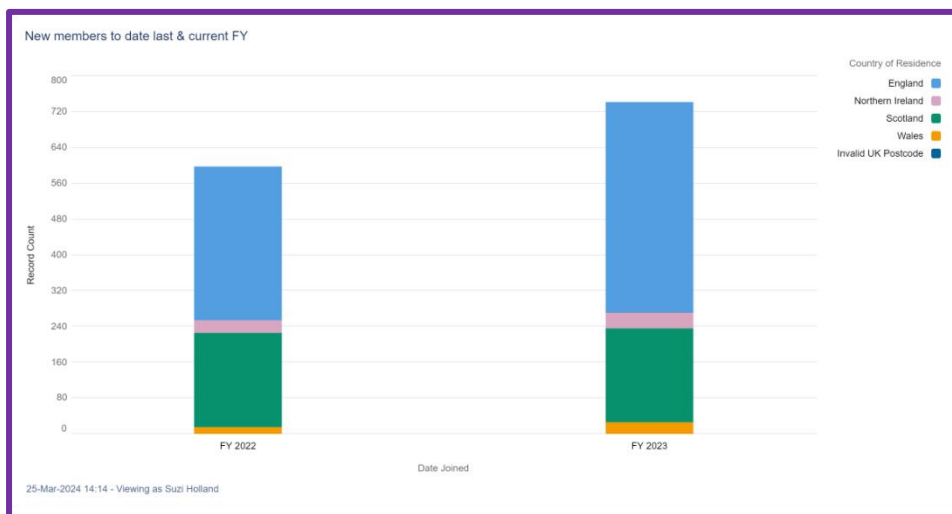
Sandra's work has further exposed the limited capacity professionals have to engage with work outside of their immediate space. However, Sandra was able to demonstrate to professionals

that the Plan can reduce their workloads and increase treatment compliance amongst patients. The challenge of capacity remains however with many professionals telling us that they do not have time to engage in any way with a new resource even if it may help in the longer term. Moving into 2024/25 we will continue to trial new ways to engage professionals and empower families to take the care plan to appointments themselves.

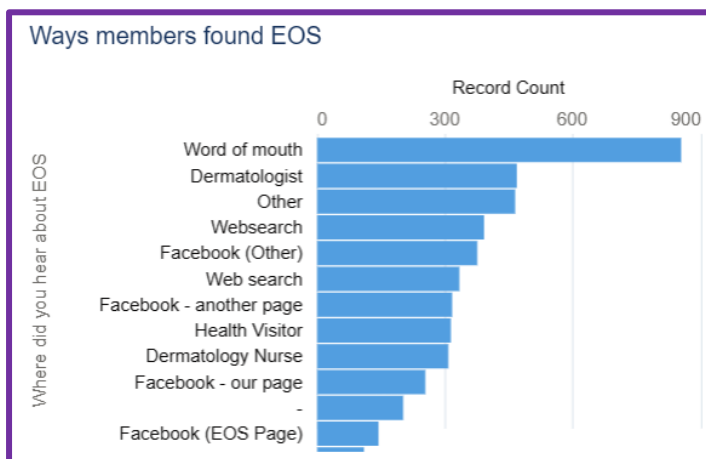
Our Service Delivery in Numbers

	2023/24
Total member families	4,254
Total child members	4,719
Welcome packs sent out	700
Initial support calls completed	164
Primary school workshops delivered	32
Events delivered	5
Facebook Group members	1,773

New members to date



Ways members found EOS



How we have made a Difference – Ethan’s Story

Ethan is eight and has had eczema since he was six weeks old. He suffers from allergies as well as eczema and despite various treatments and strengths of steroids, his eczema has never been under control or even calmed down.

Ethan’s mum, Sally, contacted EOS for a support call a few months after becoming a member. On the call she said how she didn’t take up the offer of a call straight away, as she ‘felt too emotional’ and that she might not get enough out of the experience. Instead, she looked over her Welcome Pack and read our newsletters to see what was coming up in the organisation as saw our “Grab a cuppa” sessions. Sally attended our first Grab a cuppa session in September and fed back that it had been a very worthwhile experience and went on to sign Ethan up for a High 5 Club session. She then felt ready for the call and was matched with Moira. During the call, Sally shared that her son’s dermatologist was suggesting Ethan either try phototherapy or immunosuppressants and it was the family’s choice as to which one to try. Sally and her husband were unsure what to do and were keen to get any information & resources from EOS that we could share. We shared a video of a child member’s experience of accessing phototherapy which gave Ethan the chance to see what would happen if they chose that treatment. We also brought Sally into the EOS Closed Facebook Group where she could share her questions and thoughts with other families and access information on other people’s experiences. She was very keen to join the Group and be part of the community on there.

Towards the end of the call, Sally shared her huge thanks to EOS and the support she had been given so far. She shared how she had cried with relief when she received the Welcome Pack and felt it acknowledged that EOS knows what it is like for families experiencing eczema and that we ‘just get it’. This brought her huge comfort and initial support and we are here when she needs us for the next stage of the journey.

Our Overall Impact

Impact on Carers & Children

87% of carers felt less isolated
88% of carers felt better able to cope with the impact of eczema on life
87% of carers felt supported by EOS

60% of children understand eczema and its treatments better
100% of children feel more supported/understood through our peer support initiatives

95% would recommend EOS to a friend

Biggest Challenges

1. Treatments not working
2. Child’s mental health
3. Impact on whole family
4. Impact on carers’ mental health



Equity, Diversity & Inclusion

Our commitment to EDI remains a priority and this year we have specifically focused on:

- Working with a Health Consultancy organisation to better understand the experiences of neurodiverse children with eczema and children with eczema and non-white skin. This work was in response to an increasing number of our members highlighting the additional burden eczema brings to these families. As a result of the research, we have a clear picture of what EOS must do to better reach and support these families and we have begun to seek funding to adapt our services and influence professionals in 2024/25 and beyond.
- Staff, Volunteer & Trustee training continues on Managing Unconscious Bias and Fairness, Respect, Equity, Diversity, Inclusion & Engagement (FREDIE)
- Embedding equity, diversity and inclusion at the core of our new strategy
- Improving our processes to monitor the diversity of our membership. Our Senior Management Team meet quarterly to analyse the data and respond accordingly.

“Just wanted to say thank you for the welcome pack. I definitely wasn’t expecting that. Brought a tear to my eye with all the advice given. It’s been a tough few months with my little one, and with groups like yourselves, we don’t feel alone.”

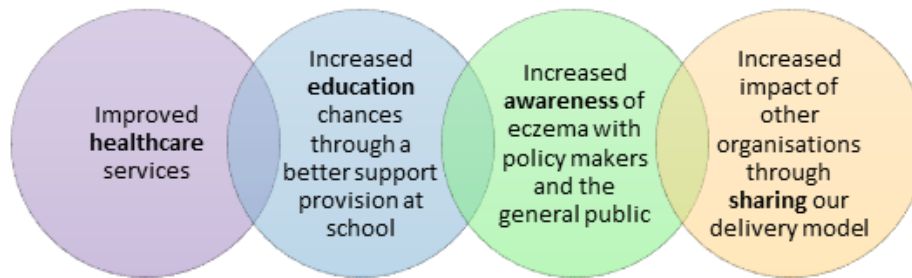
EOS Member via email



Children enjoying our Dundee event in March 2024



Our Wider Impact & Awareness Raising Work



Our wider impact work continues to grow across the UK. One of the greatest challenges we have faced this year has been influencing policy makers. Eczema is such an underestimated condition and because it is not viewed as life-ending, it is often deprioritised. However, we continue to work together with other organisations to identify opportunities to change perceptions and share the realities of living with this unpredictable condition. Below is a flavour of some of the activities we have been involved in this year.

Healthcare Improvements

- The **EOS Youth Panel** made videos for a UK-wide nursing conference to improve their practice when caring for young patients with eczema
- We presented at the **2023 Photonet Annual Meeting** to Scottish Dermatologists and Dermatology nurses involved in phototherapy for eczema patients
- We continued our work on the **A*STAR** advisory group, a research study assessing the short and long-term safety and efficacy of systemic immuno-modulators for people with atopic eczema
- We continue to sit on the steering groups of **British Association of Dermatology (BAD)**, Scottish and English Dermatology Councils, and the Appearance Collective
- We concluded our role as part of the Advisory Group of the **END-ITCH Habit Reversal research project** focused on how habit reversal can reduce scratching in children as the study came to an end. We await the next steps to see whether the approach can be taken to a formal trial
- We continued our role as part of the **Advisory Group of the Rapid Eczema Trials** which design and run clinical trials that answer questions people have about living with eczema. We are currently supporting their “Bathe” study to ascertain how often people with eczema should bathe
- We have called for **NICE** to update their guidelines for under 12s with atopic eczema and took part in a variety of health technology appraisals for new treatments including for a new treatment called Lebrikizumab to treat severe eczema
- We have worked with the **National Eczema Society** to call for better labelling on steroids to increase clarity and support the safe use of topical steroids
- Our Youth Panel presented a **Hot Topic** session at the **British Association of Dermatologists Annual Meeting 2023** about misinformation and where young people access information about eczema and the associated risks

- Our Youth Panel Chair took part in a took part in a **symposium at the British Dermatology Nursing Group** in September on mental health, eczema and social media. She shared her experiences and challenge dermatology nurses to take their role supporting the wellbeing of young people seriously. She also recorded a podcast with the BDNG Team which has been shared with nurses across the UK.

Increased Awareness of Eczema

Throughout the grant period we have developed and grown our social media channels to increase awareness of eczema, EOS and what we offer and engage with a variety of professionals and organisation across the UK and beyond. Learning for our experience to date, we have refined our content and cemented brand identities for regular events and activities including our High 5 Club meet ups and adult peer support. All content is tailored to the specific audiences of each social platform to maximise the impact it makes.

Across 2023/24, we have increased our followers across all platforms through delivering a range of content and experimenting with when, what and how we post.

- Facebook +338 followers
- Instagram +341
- X +66
- TikTok +64



"Fantastic to hear the @EczemaOutreach youth panel. Always amazing. Hope to work with you all again soon."



"Many thanks @EczemaOutreach youth panel for sharing their experience and giving valuable advice at #BAD2023."



"I did feel alone until I joined this group. So thank you." EOS member

World Eczema Day 2023

To mark World Eczema Day, we launched our #IfOnlyYouKnew campaign on our Closed Facebook Group with the titles of "Managing Eczema", "I Am Trying My Best", "Learning is Hard", and "You Can Hold My Hand". Our campaign aimed to share the realities of living with eczema as a child and parent and shared the voices and experiences of our members.

Five co-produced videos were launched across our social platforms and on our website across the week commencing 11 September. Our content reached a large audience across the week totalling 15,052 people on Facebook, 2,137 on or Closed Facebook Group, 4,111 on Instagram, 6,258 on X and 287 on YouTube. Feedback from families was that the honesty within the videos made the feel less isolated and more seen and understood.

TikTok

In January 2024, we relaunched our TikTok channel after testing various content earlier in the year. By working with our Youth Panel we learnt the importance of establishing a presence on

the platform so that the algorithm would start to share our content more widely. However, we quickly learnt that the algorithm favours dramatic content which does not align with our values. To overcome this, we have gradually been building our presence by sharing authentic content that allows individuals to get to know EOS. From this, we will start to share useful information about eczema to help combat the barrage of misinformation that exists on the platform and support young people and parents/carers to make informed decisions about eczema management.



The Press

Our members featured in a range of newspapers throughout the year (some highlights below).

Daniel and his family shared their eczema journey in a double page health feature in the Press and Journal covering North Scotland. You can read their story here – [Inverness family: 'Baby's eczema outbreak took over our lives'](http://pressandjournal.co.uk) (pressandjournal.co.uk)



Member Aria fundraised for EOS and her story was picked up by STV News and The Glasgow Times. Her mum said ‘Aria got choked up seeing herself in the paper and getting some positive attention because of her eczema.’ [Girl with severe skin condition raises hundreds of pounds for charity | STV News](#)



Policy Awareness

Patient Charter

We worked with other organisations and Sanofi to develop a Patient Charter for people living with atopic eczema. It was launched in July in Westminster, London where parliamentarians heard about the experiences of people living with eczema and what needs to change so they receive the best support and care.

The charter makes the following recommendations:

- Better access to specialist care and psychodermatology services
- People living with eczema become genuine partners in their own care
- Improved education and psychosocial support so people with eczema can better manage their condition and their mental health
- Dermatology services are supported to provide patient-centric care.

Scottish Parliament

In December, we presented at the **Scottish Parliament** with Professor Sara Brown to increase awareness of the impact of eczema on families’ lives. we shared the real challenges face by children with eczema and their families and that eczema must be prioritised by the Government moving forward. We are awaiting the next steps.

Sharing our Model– Some Highlights

- **The Vitiligo Society:** We continue to meet quarterly with the Society to share learning about our services at an operational level and to support each other with strategic projects.
- **National Eczema Society:** We continue to build our relationship with the NES and are currently assessing how we can strengthen the voices of people with eczema by working together on an awareness raising campaign
- **BAD Patient Support Group meetings:** we attend a variety of meetings to share our learning and to learn from others. We most recently have shared our experience working with a health consultancy organisation with an organisation member of the group.
- **Appearance Collective:** we remain an active member of the collective, inputting into research where relevant, sharing the experiences of our members and our learning from supporting them
- Our CEO, Suzi, was on the panel for the **NCVO** launch of their latest volunteering research and sharing our learning on volunteer-engagement. This was a new area for EOS to get involved with and a fantastic way to raise awareness of the organisation amongst a new UK-wide audience outside of Dermatology
- **Understanding Autism:** we have been exchanging learning on how to support neurodiverse children with eczema.

Our Team

2024/25 saw significant **change amongst our Senior Leadership**. Following the departure of Christine Roxburgh in February 2023, we were joined by Gavin Yates for three months. After Gavin's departure, our then Deputy CEO, Suzi Holland, applied for the role and was appointed in September. Suzi's focus has been on building for the future including a focus on our income streams and leading the development of our new strategy. Suzi recognises the uniqueness of EOS with its unwavering commitment to keeping families at the centre of every decision made. EOS must continue to grow to meet the increasing need from families across the UK however she will ensure that, as we grow, families' experiences, voices and needs will remain at the very centre.

At the end of the year our **Admin Apprentice**, Eve, moved on from EOS to pursue a new role at the local council. Eve joined us after leaving school and quickly developed a range of new skills and knowledge that we hope will support her very bright future to come.

Our **volunteer team** continues to grow with the addition of Kimberly and Eden to our Youth Panel and Jane to our office team. Our volunteers bring their own unique skills and experiences and we are currently exploring the possibility of providing one-to-one support to families through a trained and supported volunteer team.

The challenges and what we've learnt

Throughout the grant period one of our greatest challenges has been to move from being a Scotland-wide organisation to a UK-wide one whilst staying true to our roots of valuing

individual experiences and providing tailored support to every family. Capacity to meet demand has been another on-going challenge, as has navigating the differences between approaches to healthcare and education across the four nations.

We have made mistakes, including initially trying to offer the same **model of on-going one-to-one support** to families as we had done prior to our expansion. This approach resulted in staff feeling exhausted and like they couldn't offer high quality support. However, by working together with families we identified that whilst one-to-one support is important, what families often needed was a sense of community and to feel part of something bigger than their isolated experience. Since then, we have developed our peer support initiatives for children and carers and enhanced our family days to increase the opportunities for families to build relationships.

COVID-19 brought huge challenges to all and EOS was no exception. However, it also presented opportunities for us to develop our online offering which now forms a significant part of our support to families. Our team developed new skills in online facilitation and after testing different approaches, we developed models that engage children of different ages and needs no matter where they are in the UK.

The move to online during COVID also **increased our productivity** for the long term and we now utilise a range of online tools to streamline processes and reduce inefficiencies for example through our CRM, MailChimp and MS Teams and Zoom. These new approaches have helped us to free up capacity within the existing team which has been essential at a time of growth within a challenging funding environment.

During the grant period we also made the decision to close our **eczema app**. This app had been developed with young people with eczema, professionals and carers however in 2022/23 our evaluation showed it was not fit for purpose. Without significant on-going budget to continuously develop the app, we were not able to meet young people's expectations and needs and took the difficult decision to close it down. However, we have since been able to have our learning with resources in Bristol and with the company Pierre Fabre, both developing eczema apps.

Overall, we have learnt the power of community in supporting children and carers to have the confidence to self-manage complex conditions like eczema. As we have known for some time, many families feel ill-equipped to manage eczema however we have learnt that they often have more skills than they realise but their lack of confidence, exhaustion and worry mean they do not recognise them. Moving forward we will use this knowledge to support families across the UK to increase their confidence and continue to build a safe and supportive community for them to share experiences, learn from each other and ultimately better cope with eczema.



Financial Report

Portfolio Year 4

Budget as agreed April 2023 for year 4

INCOME	Budget Yr 4	Actuals Yr 4
Grant	125,615	125,615
Carry Forward	18,162	18,088
Total	143,777	143,703
DIRECT COSTS		
Welcome pack	3,000	3,332
One to one Support	500	16
High 5 Club (3-10)	500	1,189
XY Club / Youth Panel	500	63
Outreach service (schools workshops)	3,750	1,970
Events and webinars	3,000	1,792
General awareness and influencing	1,000	731
Healthcare professionals education	750	1,127
EDI & Health Psychology input	2600	3,850
Monitoring and evaluation	450	384
Website and digital platforms	956	1,811
Mobile phones & equipment	1200	885
TOTAL DIRECT COSTS	18,206	17,150
STAFFING COSTS		
Staff salaries	101,556	103,765
National Insurance	6,066	5,500
Employer's Pension	3,740	3,439
Recruitment	500	-
Staff development and expenses	1300	719
TOTAL STAFFING COSTS	113,162	113,423
OVERHEADS		
Rent and Office charges	9,500	10,627
Broadband and phone costs	224	226
Governance costs	100	228
Insurance/legal fees/payroll/accounts	1600	1,278
Other costs	985	771
TOTAL OVERHEADS	12,409	13,130
TOTAL EXPENDITURE	143,777	143,703
Balance	-	-

"The information [on] how to parent a child with eczema is so rare and spread out that it's great to have a source of it in one place that I can trust."

Parent Member, Annual Survey

